

Appendix A

April 24, 2006

DRAFT WORK GROUP BACKGROUND DOCUMENT FOR RECOMMENDATION 1.0

III. Functional PHR Standards or should this be functional medication history standards or functional registration summary standards?

1. Registration

- Registration information should contain a minimum data set that distinguishes a unique patient.
- Registration with a PHR Facilitator should be offered as a free service or with minimal cost to the individual (patient).
- Registration information should be authenticated by plan, provider or other recognized entity (TBD).
- Minimum data set should include patient demographics, insurance coverage (including dates of coverage) providers, recent service/procedures, medications (prescribed), laboratory results, diagnoses, allergies, immunizations and immunization dates.
- Registration should include a patient education briefing, including information about the privacy and security embedded in the program. PHR Facilitator should prepare an appropriate educational package with information on how the patient can share and update their PHR (med history? Registration summary?) with other providers.

2. Portability / Interoperability

- PHR Facilitators¹ cannot prevent consumer from taking their data to another plan, provider or PHR Facilitator, though this can be in the form of a printed report and need not be electronic.
- PHR Facilitators should strive to make the PHR portable in a minimum of 2 mediums (print and electronic media).
- PHR Facilitator should seek to implement PHRs from an established/published standard. No standard exists. Should we eliminate this item?
- PHR Facilitators must provide a mechanism to differentiate between data that was provided by patient, provider, external source, etc. and date provided.
- PHR Facilitators must allow updated / disputed data to be easily identified.
- PHR Facilitators should strive to provide portability of data in to EHR systems.

3. Sharing – External Sources

¹ PHR Facilitator = Entity that has the ability to produce and manage Personal Health Records (PHR) for individuals. This includes the electronic generation of a PHR and may include the ability to distribute, at patient's request, the PHR to other PHR Facilitators.

- PHR Facilitators should secure written consent of patients if data is to be shared (person or entity) other than for treatment, payment or health care operations – as long as the PHR Facilitator is a covered entity.
 - PHR Facilitators must abide by all minimum HIPAA privacy and security statutes if a covered entity or business associate of a covered entity. If the PHR Facilitator is not a covered entity, it should strive to comply with HIPAA standards as a minimum..
 - PHR Facilitator should take appropriate industry standard measures to ensure that PHI information is stored securely.
 - PHR Facilitators must comply with state-specific laws
 - PHR Facilitator should provide capability to create printed reports based on the data in the tool.
4. Data Quality & Patient Recourse
- PHR Facilitator should give patient ability to appeal legitimacy of data.
 - PHR Facilitator should provide an expedient process where patients can request updates or dispute data. Web access would be ideal but a paper process must exist; at a minimum (envision credit bureaus dispute process).
 - PHR Facilitator must provide a process where PHR Owner (patient) can request data correction from another PHR Generator or Data Source.
 - Commercial messaging should not be pushed at the point of PHR creation (to consumer).

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